IP NEWSLETTER

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Commissioner's Message

After an eventful first year, it was a pleasure for me to present the Ontario Legislature with our first Annual Report for 1988, which outlines the evolution of the Commissioner's Office, and provides statistical details on how the *Act* itself has worked.

I believe that, based on the evidence presented, the first year can be judged a success.

Almost 5,000 requests for general records or personal information were made to Ontario government institutions during 1988. These requests were evenly distributed between general records (50.8%) and personal information (49.2%). Most requests (79%) were made to ministries; the rest went to agencies (21%). In more than three-quarters (77.4%) of the cases, all or part of the requested information was disclosed by the institution, with full disclosure made in a majority of cases (55.7%). Further, 80% of all requests were completed within 30 days.

The appeal process in this Office evolved over the months, in keeping with both the unique powers of the Commissioner and the provisions of the *Act*. The appeal procedures have emphasized informality and simplicity. At the same time, the *Act*'s inherent complexity and the fact that the Commissioner is required to make a binding order to resolve an appeal, has meant that, at times the process has been complicated and time-consuming. Nevertheless, 350 appeals were received in 1988, and 36 Orders covering 79 appeals were issued. Of those appeals which were resolved during the first year (198), 53% were settled without an inquiry, generally as a result of successful mediation conducted by our appeals officers.

Not all of the issues dealt with in our first year arose as a result of appeals under the *Act*. The Compliance Branch of our Office dealt with a number of complaints, ranging from the record-keeping practices of institutions to issues relating to the security of personal information banks and how institutions deal with personal information in their possession.

The Compliance Branch also spent a great deal of time devising and implementing compliance and audit procedures, and began to conduct a number of reviews and investigations into the specific practices of several institutions.

Other activities undertaken by our Office during the first year included monitoring of the proposed Ministry of Health omnibus health-care information legislation, and providing comment on Bill 147 (the *Independent Health Facilities Act*), and the amendments to the *Child and Family Services Act*.

A number of initiatives were undertaken regarding our mandate to conduct public education. A public survey was commissioned to ascertain public attitudes and knowledge about the issues of freedom of information and protection of privacy. A brochure was written, printed and distributed throughout Ontario. This "Newsletter" and the "Summaries of Appeals" are published and distributed, throughout the year - there are four issues of the "Newsletter" produced and six issues of "Summaries of Appeals". A video about our Office has been produced and is ready for distribution. Also, members of my staff and I, spoke to numerous groups and organizations, some twenty-six in all, during the course of the first year.

Our first Annual Report supports the finding that the *Act* is off to a good start. As can be expected with any new legislation, there are some "bugs" to be worked out, but institutions have, on the whole, taken their new duties and responsibilities seriously. I particularly want to commend the work of the staff at the Freedom of Information and Privacy Branch of Management Board of Cabinet, who were responsible for coordinating and conducting the training sessions for institution coordinators and preparing the Manuals and necessary materials. As well, the institution coordinators are to be commended for their diligence and hard work under, sometimes, trying circumstances.

In the coming months, proposed changes to the *Act* will present new challenges. The review of confidentiality provisions required by subsection 67(1) have been tabled with the Standing Committee on the Legislative Assembly, and it is hoped that any amendments to the *Act* affecting these provisions will be adopted by the House in the Fall. Moreover, legislation to integrate municipalities and local government bodies should be presented to the Legislature some time in 1989. As well, the omnibus health-care information legislation will undoubtedly have an impact on our Office. It may well be that our Second Annual Report will be even more interesting than our First!

Genetic Engineering: The Ultimate Threat to Privacy

As with previous pioneering developments in technology, the forthcoming developments in biotechnology are raising new socioeconomic issues. Closely tied to this are moral and ethical concerns as to the use of the new technology and how it will impact on our lives. What we will be faced with in the 90's will be nothing short of a reading of our genetic code -- something which has always remained private in the past because we lacked the means by which to "read" this information. That will no longer be the case, however, in the not-so-distant future, and no one knows what type of Pandora's box this may open.

Genetic Overview

As you may know, all higher life organisms contain DNA (deoxyribonucleic acid) within their cell nuclei, from which all metabolic functions are directed. The DNA molecules are joined with protein molecules that are also present within the centre of each cell. Out of this union, the structures known as chromosomes are formed. Each human cell contains 46 chromosomes, arranged in 23 pairs, such that the 23 derived from the mother are matched with the 23 derived from the father. In this manner, offspring inherit DNA which causes their own metabolic growth and development to resemble the patterns displayed by their parents and ancestors.

Arranged in these 23 pairs of chromosomes are an estimated 50,000 to 100,000 genes, which are essentially sets of instructions at the molecular level, that direct human growth. This means that each chromosomal pair holds a collection of up to 4,400 genes. Due to the minute size of these chromosomes, scientists cannot observe them under even the strongest of microscopes, and must turn to elaborate chemical procedures in an attempt to identify various genes. This is such an arduous task that the chromosomal location or "address" of only about 2% of all human genes has been discovered to date.

Through a process known as genetic sequencing, researchers have been able to locate the genes responsible for certain disease states such as muscular dystrophy, cystic fibrosis, Down's syndrome and a number of others. Hypothetically, it should be possible one day to map all of the characteristics, both physical and personality traits, that make each of us who we are. The enormity of such a project is truly mind-boggling: there are up to 100,000 genes in a single strand of DNA, with literally millions of chemical base pairs (or nucleotides -- the chemical component of genes), which would need to be discovered in order to identify the existence of various traits. While it may seem that such an ambitious undertaking would be light years away, it is in fact, just around the corner.

The mapping of the human genome or the complete set of genetic information that makes us who we are, is presently underway. The United States Congress has estimated this massive project to require at least three billion dollars and ten to fifteen years to complete. The Japanese, in addition to various research teams from Britain, France, West Germany, Asia and New Zealand, are also in the process of exploring the mapping of the genome.

The issues that this project raises are of such a magnitude that they have been the subject of a number of recent articles in popular magazines: *Newsweek*, *The Wall Street Journal*, *Science*, *American Health*, and most recently *Time* magazine, featured this as its cover article several weeks ago.

So, you might ask, why is this subject capturing so much of the popular press's attention? Well, the changes that this mapping research heralds will be both cause for great celebration and great concern. I will not focus on the wonderful medical discoveries that such research will invariably lead to. These are far more self-evident and thus, will not be explored in this short time. The areas of concern I think, are less evident to most -- so I would like to highlight a few of these in the time remaining.

A New Form of Discrimination

As we approach the 90s we are on the cusp of a new age -- the Biotechnological Age. Jeremy Rifkin, president of the Foundation of Economic Trends in Washington, D.C. cautions us that on the dawn of this new biotechnological age, the great civil liberties issue will be the right to genetic privacy -- one that should be accompanied by tremendous public policy concern: "This is the right to control your genetic information and not have it at the beck and call of the institutions that oversee society."

At the recent Couchiching conference, a think tank on biotechnology warned us of a new form of discrimination, more harmful than that based on race, religion or colour. Rifkin warned that "it will bring discrimination into your workplace, into the school yard and into the community". Virtually everything that there is to know about us may one day be open to public scrutiny if this is not protected. Just think about it. Compared to our present concerns such as the confidentiality of medical records and maintaining the security and privacy of personal information, a printout of our genetic code and the information resulting from that would leave virtually no stone uncovered -- the colour of your hair, various personality traits, how intelligent you are, whether you have an aptitude to do what your job requires you to do, and so on.

Genetic Screening and Workplace Hiring Practices

Let me now turn to how genetic screening may affect workplace hiring practices. It appears that big companies like to test employees and new job applicants. Forty-three per cent of the largest American firms including IBM, A T & T and 3M have all implemented drug testing programs. A recent article by Nolan and Swenson, 1988, referred to the "employers' inability to resist the urge to exclude potentially costly employees".

Workplace screening practices highlight a number of the contentious issues surrounding the application of the new genetic biology. Such things as, "the current pressures to curtail spiraling employee health care costs could easily tempt employers to rely on genetic 'predictors' to guide their hiring decisions." (Nolan and Swenson).

As if that wasn't bad enough, add to it the enormous folly of basing your discriminatory hiring practices on information that may never materialize. Most genetic screening tests involving multiple genes will be less predictive than a direct examination for specific conditions. This is due to the fact that one's genetic read-out may indicate some disease states which you may be **predisposed** to getting, but the key word here, is "predisposed" -- you may get it, you may not. It depends on a number of factors, not the least of which are environmental factors.

Genetic research has established certain levels of association between the occurrence of genetic traits and the probability of acquiring specific diseases. In some cases the association is very direct, but far more often, the link is very indirect. Certain genetic compositions are known to increase the risk of acquiring particular diseases, but often this never occurs and the conditions under which it may occur are unknown.

Applying genetic screening programs before fully understanding the nature of the relationships between the genetic trait and the disease is of dubious merit since it may lead to the stigmatization of individuals on the basis of diseases which they may never acquire.

The U. S. Congress's Office of Technology Assessment (OTA) conducted a survey in 1988 concerning the attitudes of executives in various corporate circles with respect to the probable future of genetic testing. Hewitt and Holtzman of the OTA concluded that genetic testing is expected to expand in future years: "In terms of screening in the workplace, nearly half believe that by the year 2000, employers are likely to use genetic tests to screen job applicants."

Workplace screening practices hold the distinct possibility that individuals with specific genetic traits or genetic susceptibilities such as predisposition to depression or paranoia, will be denied access to employment. For example, one author asks: "would a company want to invest a great deal of money and time in a fast-track manager it knew would have a heart attack in mid life?" Would a company hire you for a job in a chemical environment if it finds you have a predisposition to cancer? Rifkin asks, "... should schools know that your offspring has a predisposition to depression? ... Should your employer know if you have the Alzheimer gene?"

The potential for widespread discrimination is considerable: employers could demand a totally healthy work force through the genetic screening process, and those whose genes did not meet predetermined standards, may not be considered. This, despite the fact that one's genetic profile may at best indicate predispositions towards particular conditions, not necessarily proof of their eventual existence. Couple this with the fact that the causes of our behaviour are certainly not attributable solely to our genotype. Unfortunately, I do not have the time to explore the nature vs. nurture arguments as to the causes of human behaviour. This debate has existed for many years and will, no doubt, continue to do so, with the pendulum swinging back and forth between the respective influences of heredity vs. the environment. Suffice it to say that environmental factors contribute enormously to our behaviour (as studies have demonstrated on twins raised apart in totally different conditions).

Data Collection and Database Accumulation

Another major area of concern is the creation of central databases which would act as repositories for the extensive information generated by the genetic screening process. Paul Berg, a Professor of Biochemistry at Stanford, foresees a time when we will all have a genome "credit card" in which all of our genetic liabilities would be listed. Does this sound like science fiction?... It shouldn't. In the near future, all Ontario residents may have a health identification number stored on a credit card-looking device called a "smart card", and it would not be that great a step to think that our medical histories could also be stored on such a card in the not-so-distant future.

One of the major concerns facing privacy advocates surrounds the issues of data collection and database accumulation. If a system was in place requiring each person to carry a genetic code card, then there would also exist for each individual a record, in at least one database, with information that could be used to identify not only one's physical characteristics, but also various disease conditions and disease susceptibility, mental capacity, reproductive ability, personality characteristics, and assorted other pieces of information. The way that such databases would be used and kept secure would determine the extent to which individual privacy rights were protected. The major questions, therefore, surround not only the collection, but also the storage and use of DNA data banks.

Of course, the mere existence of such databases can be the source of anxiety for numerous individuals, particularly those who understand the potential abuses that can occur, whether intentionally or unintentionally, not to mention the ever-growing room for error. Some argue that once these databases are in place, there will be no way to protect the confidentiality of this information since it will be in such great demand. Operating from this premise, they advocate gathering only data that everyone agrees can be shared publicly. The other point of view, shared by many data protection agencies, is to avoid collecting such information at all, unless necessary for such things as police identification purposes or the operation of government programs. That may take care of the public sector, but still leaves the collection and use of such information by the private sector wide open.

In the private sector, such information could be shared with insurance companies, health care organizations, pharmaceutical companies, and so on. Without strict regulation, genetic tests will likely be used by life insurance companies to exclude those who possess traits which might eventually lead to disease states. The problem, once again, is that some types of genetic information can only point to a **predisposition** towards certain disease states. Unlike medical information containing actual diagnoses of existing conditions, genetic information is potentially much more damaging since people may never develop the disease states that they are predisposed to, and on the basis of which, they have been denied insurance.

The Need for Regulation and Legislation

In order to prepare for the arrival of such issues and provide a forum for discussion, Rifkin has demanded that a "human genome policy board" be formed in the U.S. Congress, consisting of affected constituents. You may consider this a rather ambitious undertaking, but it wouldn't be the first time: Rifkin lobbied for and was successful in getting a Bill passed in the House of Representatives against the patenting of animals. Yes, that's right -- the patenting of animals -- another biotechnological marvel.

We too, should start thinking in terms of regulating the eventual collection, use and disclosure of such information. While it may seem far off, it is not going to be ten years before anything is learned. As Dr. Daniel Nathans, a professor of molecular biology and genetics at John Hopkins said, "You don't need to have the whole project done before you start learning something...Within one to three years, biologists hope to have cheap and accurate probes to detect illnesses known to be caused by defects in a single gene, such as susceptibility to certain kinds of cancer." Another condition that could yield to genetic research of this type in the near future is manic depression, which is said to afflict 1% of the U.S. population, or 2.5 million people.

We must start thinking about this new technology **sooner** rather than later. There are many choices to be made in terms of the permissible and desirable ends to which we can and should apply this new biotechnology. Efforts to legislate the appropriate balance between genetic progress and genetic privacy will be very difficult. Putting into place a comprehensive policy framework would first require the resolution of many inherently difficult ethical dilemmas. But the time for discussion and debate is now. This is one area where we do not want to risk developing policy guidelines and legislation after the fact -- in a post-hoc manner that is reactive in nature.

In closing, I would like to refer to *Time*'s recent article, "The Perils Of Treading On Heredity", in which they concluded that "just like a credit card or an arrest record, a DNA analysis could become part of a person's permanent electronic dossier. If that happens, one of the last vestiges of individual privacy would disappear." Let us collectively make sure that does not happen.

An abridged version of Ann Cavoukian's paper, presented at the ASAP Conference, Ottawa, April 14, 1989.

Copies of the complete text may be obtained from the Commissioner's Office (with complete footnotes referenced).

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